



SPECIAL NEWS FOR SPECIAL NEEDS



Issue 7

Spring, 2004



Hello and happy spring! Or...is it summer already? The weather seems to go back and forth each day. Imagine how confused our flowers and plants must be! In this issue you'll find an update from Michelle Lamers on the Higher Education Round Table that was held on April 28th. Michelle is still looking for more parents to participate in New Scripts! Also in this issue are several stories from parents who want to share their experiences with other families of children with special needs. If you would like to share your story, please call Sandy or Kellie or you can e-mail them at the addresses listed below. We hope you have a safe and happy summer season.

Kellie & Sandy

Family Support Specialists

Kellie 302-995-8617 kellie.mckeefery@state.de.us

Sandy 302-422-1335 sandy.ward@state.de.us



Please join us for a very informative Family Forum featuring Maria Mendoza of the Parent Information Center. Maria will do an overview of **TRANSITION**, a topic of interest to all families of children with special needs.

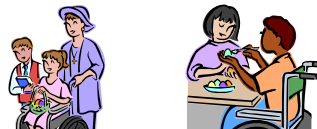
DATE: Thursday, September 16th

TIME: 6:00 - 7:30 p.m.

PLACE: CHILD DEVELOPMENT WATCH
18 NORTH WALNUT ST., MILFORD

**PRE-REGISTRATION REQUIRED. PLEASE CALL
SANDY WARD AT (302) 422-1335.**

IDEA'S INCLUSION MANDATE



WORKSHOPS OFFERED

The Public Interest Law Center of Philadelphia in collaboration with Delaware's Community Legal Aid Society, Inc. will present a one-day workshop to provide technical assistance and training for families, advocates, teachers and service providers seeking to implement the IDEA's Inclusion Mandate for students with disabilities in Delaware. The workshop will introduce participants to the history, accessibility and current state of public education for children with disabilities in Delaware. Participants will explore how to include students with disabilities in regular education.

New Castle County - Sheraton Suites, 422 Delaware Ave.,
Wilmington

Friday, September 17, 2004 9:00 a.m. - 4:00 p.m.

Kent County - Sheraton Dover Hotel, 1570 N. DuPont Hwy.

Saturday, September 18, 2004 9:00 a.m. - 4:00 p.m.

Sussex County - Two Sessions will be scheduled for the Fall

Workshop Fees: \$25.00 per person covers breakfast and lunch. A second family member can attend for only \$15.00. A limited number of scholarships are available on a first-come basis.

Register With:

LaTrice Brooks, The Public Interest Law Ctr. of Philadelphia
125 South 9th Street, Philadelphia, DE 19107
215-627-7100 (ext. 232)



Delaware Health and Social Services, Child Development Watch



WELCOME TO THE WORLD OF HARLEY POORE

By: Amy Poore



Harley was born to us on March 1, 2001 at thirty-five weeks. She had to be rushed to A.I. duPont Hospital for Children the same day for an open-heart operation. She was diagnosed with Digeorge Syndrome (VCFs) two weeks later. Then they noticed she had a soft palate so that needed to be repaired. At fourteen months, she had her first surgery. Oh, I meant to mention that she has a g-tube for feedings. The first surgery was unsuccessful due to hemorrhaging and we later found out that she has Von Willebrandts Disease, a blood clotting disorder. Now she will need to be followed by a hematologist the rest of her life. She is on the nebulizer every four hours to help with her breathing. We are currently waiting for test results that she had done recently for platelet aggregation since she has had some bruising and was sick a lot this year. Although Harley has all these medical issues, you cannot tell because she acts and plays just like a normal three-year-old would. Thanks to all the nurses and therapy she received at the Children's Secret Garden and Easter Seals. If it weren't for their help, I don't know where we would be today with her. You can visit Harley at her website and learn more about her.

[Http://www.caringbridge.com/de/harleysdigeorgepage](http://www.caringbridge.com/de/harleysdigeorgepage)



This selective program is designed to train young adults with disabilities and the parents of young children with disabilities in advocacy skills. Students meet for eight weekends from January through September each year. Each weekend session goes from Friday noon to Saturday afternoon. The training is conducted at the Dover Sheraton. Both national and local experts are brought in to train up to twenty-five (25) students in the skills needed to be self-advocates or to advocate for their children. The Developmental Disabilities Council pays for the students' room and board for each session, plus travel and other required expenses to attend the training. Recruiting for the next class begins in July. For more information contact Marsha Mills at (302) 739-7193.

PARENT TIPS

Source: Illinois Early Learning Project, University of Illinois
<http://www.illinoisearlylearning.org/tipsheets/gift-conversation.htm>

Conversation

Find time to talk with your child! Make it a habit to turn off the television or computer or car radio, and use those moments for conversation. Talking with adults is the best way to expose a child to new words and ideas.

- When you can, include your child when talking with other adults.
- Set aside a regular time to talk with him—bedtime or mealtime are ideal.
- Rephrase what your child says and build on it, showing you understand. "You're hot? The sun is warm today, isn't it? Would you like a cold drink?"
- Pause after speaking to your child, giving him time to respond.

Routines

Build vocabulary during your everyday routines.

- When you shop, talk about what you will buy and how you will use it. Discuss size and weight. Is a package small or large, heavy or light?
- When you're cooking dinner, discuss what you're cooking and what foods can be eaten raw. Talk about where foods come from.
- Watch television with your child. Talk about what you are watching together, especially if you think the child might have missed some word meanings. Look for children's programs that teach in fun ways, such as "Between the Lions" or "Sesame Street."
- Talk about the programs. Talk about where you're going and what you see. "Do you think there might be a bird's nest in that tree?" "Is that building a bank or a hospital?" "How do you know?" "Who do you think might work there?"
- Label objects with your words. "That flower is a rose. Look at the caterpillar." Learn with your child. "I don't know what that bug is. Let's ask the librarian to help us find a book on insects."

Learn more about increasing your child's vocabulary at these Web sites:

Teach your kids new words

<http://pbskids.org/lions/tips/teach-words.html>

Activities to Encourage Speech and Language Development

<http://www.asha.org/public/speech/development/Parent-Stim-Activities.htm>

Building Children's Background Knowledge and Thinking Skills

http://www.ed.gov/teachers/how/early/teachingouryoungest/page_pg11.html#background



PARENTS' CORNER



ROLLER COASTERS ARE SUPPOSED TO BE FUN

By: Jennifer Pulcinella (Lewes, DE)

We already had our vacation to Las Vegas paid for; hotels were booked, flights were scheduled, and I was only 6 months pregnant, so we went. It was going to be our “last hurrah” before the baby was born and we had big plans for our time there. Delaware in October is nice and all, but we had lived in Las Vegas several years earlier and were anxious to show it to friends. Two nights into a six-night stay I started getting sick to my stomach. “Probably food poisoning” was what the gum chewing paramedic said; and I was off through the casino to the nearest hospital. Once there, they did all the usual tests for a pregnant woman and discovered protein in my urine. Right after starting magnesium I had a seizure. My blood pressure had shot to 220/150 and it was making me nauseous. The last thing I remember was 1:37 a.m.

When I awoke I was in a different room (& hospital) and a nurse was handing me a picture saying “Congratulations! It’s a girl! 1lb 4 oz.” She handed me a Polaroid of the little baby I remembered from her sonogram 11 days earlier. “But I had food poisoning?!” Claudia Jean was born at 7:28 a.m. October 20, 2002 at 26 weeks. As I sat there waiting for my husband to arrive I kept trying to digest what had happened. We didn’t even sign up for Lamaze, let alone take any classes, and now she’s here. We entered the NICU to see our little one and were immediately struck with the realization that preemies are born all the time (and to prove it, here are 20 others). She was 12 inches long and hooked up to more tubes and machines than I knew existed. “When can we take her home?” “When’s her due date?” January 28th.

We didn’t leave Las Vegas for 114 days. Little did I know that the Ronald McDonald House would be having a lull and could let us stay the entire time? That Las Vegas had such a great bus system? That I couldn’t “run to catch a bus” right after having a C-section. We went to church that first Sunday and on the way out the pastor asked if we needed money. We declined but did ask about transportation. Our weekly car rental was going to run out soon and we knew that money would go fast. A few days later, a man had knee surgery and couldn’t drive his stick shift anymore; so he donated his truck to the church. By the following Sunday we had our car. We went through Halloween, Thanksgiving, Christmas, New Year’s, and finally, for Valentine’s she had grown to a hearty 5 lbs. Claudia was still having problems with her breathing. Growing up on a vent created a narrowing of her airway (subglottic stenosis) and the scar tissue caused her to squeak when she breathed off the vent (strider). So “Squeaky” needed a procedure done that they couldn’t do in Las Vegas and she caught an air ambulance to the Children’s Hospital of Philadelphia (CHOP), 200 miles from our home.

In the first 2 weeks, she had a tracheotomy and was transferred to CHOP’s Seashore House. By May 5th we had learned her trach care and she was adapting well to life on a vent. It was time to go home, 200 days from when we left and on the anniversary of the day she was conceived. We may have missed ALL the major holidays but we were GOING to catch Mother’s Day! And there will never be another like that one.

Jennifer



EXPECTED VISUAL PERFORMANCES

Optometric Extension Program Foundation, Inc.

(<http://www.oep.org/parentsq.htm>)

Birth to 6 Weeks of Age

- Stares at surroundings when awake
- Momentarily holds gaze on bright light or bright object
- Blinks at camera flash
- Eyes and head move together
- One eye may seem turned in at times

8 Weeks to 24 Weeks

- Eyes begin to move more widely with less head movement
- Eyes begin to follow moving objects or people (8-12 weeks)
- Watches parent's face when being talked to (10-12 weeks)
- Begins to watch own hands (12-16 weeks)
- Eyes move in action inspection of surroundings (18-20 wks)
- While sitting, looks at hands, food, bottle (18-24 weeks)
- Looking for and watching more distant objects (20-28 weeks)

30 Weeks to 48 Weeks

- May turn eyes inward while inspecting hands or toy (28-32 weeks)
- Eyes more mobile and move with little head movement (30-36 weeks)
- Watches activities around him for longer periods of time (30-36 weeks)
- Looks for toy he drops (32-38 weeks)
- Visually inspects toys he can hold (38-40 weeks)
- Creeps after favorite toy when seen (40-44 weeks)
- Sweeps eyes around room to see what's happening (44-48 weeks)
- Visually responds to smiles and voices of others (40-48 weeks)
- More and more visual inspection of objects and persons (46-52 weeks)

(Continued – top of next column)

12 Months to 18 Months

- Now using both hands and visually steering hand activity (12-14 months)
- Visually interested in simple pictures (14-16 months)
- Often holds objects very close to eyes to inspect (14-18 months)
- Points to objects or people using words "look" or "see" (14-18 months)
- Looks for and identifies pictures in books (16-18 months)

24 Months to 36 Months

- Occasionally visually inspect without needing to touch (20-24 months)
- Smiles, facial brightening when views favorite objects and people (20-24 months)
- Likes to watch movement of wheels, egg beater, etc. (24-28 months)
- Watches own hand while scribbling (26-30 months)
- Visually explores and steers own walking and climbing (30-36 months)
- Watches and imitates other children (30-36 months)
- Can now begin to keep coloring on the paper (34-38 months)
- "Reads" pictures in books (34-38 months)



Please Note: The ages given are only guidelines – children develop at different rates. If you have any questions about your child's development, please talk with your primary care physician or your Child Development Watch family service coordinator.





My name is Michelle Arthurs, I am married to David and we have 4 fantastic children, two sons, Dave, 20 and Devin, 19, who just completed their freshman year at Indiana Wesleyan University and a daughter, Kayla who is 13, a freshman in high school and Kennedie who will be 2 in July.

It is my great opportunity to tell you about our daughter, Kennedie. Our pregnancy with Kennedie went very smoothly, nothing exciting; I didn't even have morning sickness. We went to all our appointments, had all the tests, ultrasounds etc. So on July 23, 2002, we went into labor at 5:00 a.m. and 4 1/2 hours later we had a beautiful baby girl. Ten fingers, ten toes, a perfect little angel. Three days later, just before being discharged from the hospital, a murmur was discovered. Our pediatrician recommended we take Kennedie to see Dr. Roger Ruckman, a cardiologist. An ultrasound was done and Dr. Ruckman explained that Kennedie's heart was in terrible shape, three holes and a valve that was torn from top to bottom. He stated that it could all be corrected with open-heart surgery. Of course, our first thought was "She can't have open heart surgery, she is just a baby!" That of course scared us but what he said next, devastated us. He said that Kennedie's heart condition was associated with her Down syndrome. Down syndrome! What Down syndrome! She doesn't have Down syndrome! No one has said anything about Down syndrome! I picked Kennedie up from the examination table in Dr. Ruckman's office and David and I held her and each other and cried. Poor Dr. Ruckman had assumed we knew. He let us cry and kept telling us how sorry he was. After that we needed answers. "Dr. Ruckman, are you sure?" "How do you know?" He answered our questions as well as he could and suggested that we have a genetics test done. So in September, we met with Dr. Bartoshesky who calmed our fears and explained that he was going to do a blood test on Kennedie. After the longest two weeks of our life, the test later confirmed that Kennedie had been born with Down syndrome. This was quite a shock when you think all is well with the world and then you are told open-heart surgery and Down syndrome in less than a month and your baby is only 3 months old. We knew nothing at all about Down syndrome. We wanted to put Kennedie in a bubble and keep her there. We didn't know what to do, so we started praying. We didn't know what our future held but we knew Who held our future. We knew God would provide for us. AND, OF COURSE, HE DID JUST THAT!

A couple of days later, we got our answer. The phone rang and the person on the other end introduced herself as Helene Diskau and told me that she was with Child Development Watch (CDW). She told me that they help families with special needs children. She asked if she could meet with us so that she could share what they could do for us. We met with Helene and what a great day that was! Child Development Watch has given us guidance and support but most of all courage to believe in ourselves as parents of a special needs child. She directed us to all sorts of services, like PDDN (Preschool Diagnostic & Developmental Nursery) and the many specialists that we visit throughout the year. When Kennedie had her open-heart surgery at 10 months old to correct the defect I spoke of earlier, the insurance company decided not to cover the \$100,000 surgery because it was not going to be done in Delaware. Helene helped us communicate with the insurance company and our medical bills eventually got paid.

CDW and PDDN answer every question, listen to our needs and goals we have for Kennedie and then lead us in the right direction to reach those goals. The staff at CDW and PDDN are right there along side of us cheering her when she reaches a goal, as well as when she doesn't. We regroup and start again, together. Our family is truly blessed to have CDW and PDDN. They help us face the challenges with confidence and we know that Kennedie will be more than we could ever have hoped or imagined because of the friends at CDW and PDDN.

There is a whole world of individuals out there just waiting to help us. What we thought was a tragedy, turned out to be a wonderful experience. We have discovered a wonderful world through Kennedie's eyes. One of the many wonderful things that Kennedie can do is make strangers smile at her. She has this contagious smile that people get sucked in to. She adores her daddy, night-night bear and music. She is tough and nothing gets her down, and she is soon to be only 2 years old. Given the opportunity, Kennedie will prove she has no limitations, she can hang with the best of them. Several months ago, David and I were interviewing daycares for Kennedie and a staff member stated that Kennedie would be the only girl with six boys. She asked if that would be a concern for us. We looked at each other and smiled. We told the staff person that she should be concerned for the six little boys. Look out world, here comes our Kennedie!

Michelle



Michelle Lamers

Kathy Janvier

Ed Broadbelt

Nancy Smith

In the last issue I invited interested parents to join the Family Inclusion Project for Delaware New Scripts and become advocates for children. I received an overwhelming response and have had the pleasure of meeting and working with truly great people. In spite of the personal challenges each is facing, they have decided to join our cause to help make changes in the way early interventionists are trained. The main goal of this project is to include families in classrooms so future teachers, aids, therapists, nurses, doctors, and others who will work with children in their careers, have a better understanding of what it is like to parent and interact with children who have special needs.

As part of our efforts parents participated in a Higher Education Round Table titled "Families and Faculty: Teaching Together in Early Intervention." It was held April 28 at Delaware State University in Dover. Faculty from various colleges and universities in our state attended and had the opportunity to hear from Camille Catlett of the University of North Carolina. Camille, an expert in the area of changing the way the future work force is trained, led us in an informative day, which helped attendees to see ways we could work together to make families in classrooms become reality.

Our work is just beginning, and we welcome any and all parents who still want to join us. We will be meeting to discuss our future path. We want to be sure all interested parents are included despite any obstacles. We are about inclusion so please contact me even if there are transportation issues, language barriers, or other circumstances, which may prevent your involvement. I look forward to building this project with your help. Contact me at (302) 999-7394 (mailbox #7), toll free at (888) 547-4412 (mailbox #7), or at Lamersmm@aol.com.

Thank you.

Michelle Lamers

